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**Article**

# *Cystic Fibrosis: A Pocket Guide*

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**Abstract**

In 2010, an iPad app titled '*A Patient's Guide to Cystic Fibrosis'* was developed for use by Cystic Fibrosis (CF) clinical nurse specialists during a patient's annual review. Feedback from pseudo-Cystic Fibrosis patients and NHS staff including CF clinical nurse specialists and respiratory consultants about the appearance, usability and content of the app and iPad interface, and the appropriateness of the app for CF patients was positive. The visual images, animations and interactive elements of the app were sufficient in providing an engaging experience for the user. The app was deemed suitable for patients and set a foundation for the development of comprehensive and interactive CF patient information learning tools.

Since 2010, the prevalence and popularity of iPad apps in healthcare has soared and apps now have the capability to include more interactive touch-based experiences with digital content such as 3D models. The original iPad app was re-developed as an Apple iBook and an Android app titled '*Cystic Fibrosis: A Pocket Guide'.* This paper describes the design, development and feedback on the original iPad app and its subsequent variants, and concludes with reflections from the specialist CF nurses, who have continued to use pocket guide over a 10 year period.

**Introduction**

Cystic Fibrosis (CF) is one of the UK's most common life-threatening, inherited diseases caused by a genetic mutation and affects almost 11,000 people in the UK, with over two million people carrying the faulty CF gene (Cystic Fibrosis Trust, 2020). The high prevalence of CF in the UK population has placed pressure on hospitals and NHS staff to provide thorough and engaging Cystic Fibrosis patient information materials to help CF patients to understand their disease and its management.

Cystic Fibrosis patients undertake a comprehensive annual review as a means to check for complications, document any difficulties and worries, provide continuous CF education, discuss any concerns, create a treatment plan, and make suggestions for self-management for the upcoming year (Peebles, *et al.* 2005). The review involves the clinical examination of the patient, collection of sputum, stool samples and cough swabs for microbiological culture; lung function tests; chest X-Rays, CT scans and abdominal ultrasounds, and review of inhaler techniques. Physicians involved in the annual review include respiratory consultants, CF clinical nurse specialists, physiotherapists and dieticians.

This information accumulating process not only benefits the patient concerning their illness and its management but also enables the families of the patients to understand what Cystic Fibrosis is, why certain medical tests are required and how to lead a lifestyle that is appropriate for their disease. (Peebles, *et al.* 2005). The education and management of CF in teenagers and adults is especially complex, as it requires contributions from numerous medical practitioners, social workers and family members. The communication of medical problems and disease information with young adults that possess varying degrees of national education is difficult and it requires skill, expertise and an ability to encourage self-education (Webb, 1995).

Although clinicians and other healthcare workers aim to provide CF patients with an understanding of their illness, it is not always possible to provide thoroughly comprehensive and engaging information in time-limited clinics or appointments, often leaving the patients with a misunderstanding of their disease and its daily management. Adult sufferers more frequently describe unmet needs for disease information, with the self-management of the disease reported as the area most in need of additional support (Anand, *et al.* 2014; Sawicki, *et al.* 2007). The exception are patients who are more frequently hospitalised and therefore spend more one-on-one time with appropriate health care professionals (Conway, et al. 2008).

Written sources of information including leaflets and booklets are vital sources of information for CF sufferers, and historically such materials usually provide satisfactory information regarding the disease and its subsequent complications (Loeben*, et al*. 1998). However, leaflets and textbooks may be unsuitable for patients who are unwilling or unable to learn comprehensively about CF treatments and self-management. Patients who spend the majority of their childhood and teenage years in and out of hospitals and not in school, may not possess the ability to learn from interaction with text-heavy, written information or may be unwilling to read such information, as their exposure to the national education system is limited (Sawicki, et al. 2007)**.** Other challenges facing developers of patient information resources include varying literacy, physical and mental disabilities and spoken languages of the users (Briggs, *et al.* 2014; Moshtaghi, *et al.* 2017).

In an analysis of responses to an internet-based questionnaire available through numerous Cystic Fibrosis websites, Widerman (2003) reported that adult sufferers had a limited or non-existent knowledge of the disease at the time of their diagnosis and 26.9% of respondents stated that the information they were given at diagnosis was

insufficient, and they would have liked more information specific to the effects and complications of CF.

The Internet is an alternative option for patient learning as it allows for easy access to information regarding numerous diseases and related medical material, and this is also true for Cystic Fibrosis where bespoke websites including the '*Toronto Adult Cystic Fibrosis'* ([www.torontoadultcf.com](www.torontoadultcf.com)) website have developed, implemented, and evaluated (Anand, *et al.* 2014). Whilst the ability to access information through the Internet may increase a patient's willingness to learn, the information presented online is not always subject to rigorous guidelines and procedures are not in place to supervise the accuracy of the content of online material (Richards, *et al.* 1998). In a 2004 study conducted by the American Medical Association (AMA) the words 'Cystic Fibrosis' were entered into an Internet search engine and one hundred websites that were produced as a result of the Internet search were analysed. The results of the study showed that written information about Cystic Fibrosis, which was supported by references and had been peer-reviewed, accounted for only thirty eight of the websites available, and that some of the information was inaccurate or misleading. (Anselmo, *et al.* 2004). While information on the Internet has its drawbacks, it does provide a platform for the hosting and easy distribution of multimedia resources.

Health education materials frequently place emphasis on images, with the role of the text being to explain the information presented by images (Finan, 2002). Images supported by written text have been reported to increase recall of key health information and reduced possible misunderstanding (Houts, *et al.* 2006). A multimedia learning environment is more than just a leaflet with images. They employ a mix of appealing images or animations and information that can be tailored to suit a specific subject matter. They are often easy to use, informative and more enjoyable than reading written

text alone (Jones, *et al.* 2001). Mayer (2003) also states that multimedia learning can help people to learn better from words that accompany pictures or animations more than words alone, and that advanced multimedia technologies help promote deeper learning because they present images, animations and words together. This is important to think about when developing computer-based multimedia environments (Mayer and Moreno, 2002).

Interactive technologies and interfaces, including the Apple iPad, engage users by providing a physically interactive experience, and facilitate the development of content that can be used as learning tools (Dale and Pymm, 2009). These devices can host multimedia learning environments downloaded from the Internet, make key health information portable and more readily available in the absence of the Internet once downloaded, and ultimately encourage patients' knowledge absorption and retention rates (Moreno, 2006; Moodley*, et al.* 2013; Pandey, *et al.* 2013; Briggs, *et al.* 2014; Sahyouni, *et al.* 2017).

In 2010, the year the Apple iPad was first released, a collaboration between a postgraduate Medical Art student and two CF clinical nurse specialists led to the production of an interactive CF patient information iPad application as part of a taught-postgraduate research project. The aim for the iPad app was for it to be used by CF patients and clinical nurse specialists during a patient's annual CF review, and to establish whether patients were more willing to engage in learning about their disease if they could interact with a predominately visual and interactive patient information tool. The application centered on the creation of three-dimensional anatomical computer models that would highlight the organs and systems affected by Cystic Fibrosis. The images would be accompanied by animations and written information regarding the

normal anatomy of the organs involved and how CF affects them, and detailed

information about the annual CF review.


**Methods**

An Apple iPad (first generation) application was developed (figure 1) using two-

dimensional (2D) diagrams, 2D renderings of three dimensional (3D) models, 3D

animations, and written content was adapted from the UK Cystic Fibrosis Trust

'Standards of Care' documents

(https://www.cysticfibrosis.org.uk/~/media/documents/the-work-we-do/care/consensus-

docs-with-new-address/cystic-fibrosis-trust-standards-of-care.ashx?la=en), with

additional text supplied by CF clinical nurse specialists from the Respiratory Unit at

Ninewells Hospital, Dundee. The 2D diagrams and rendered 3D illustrations were

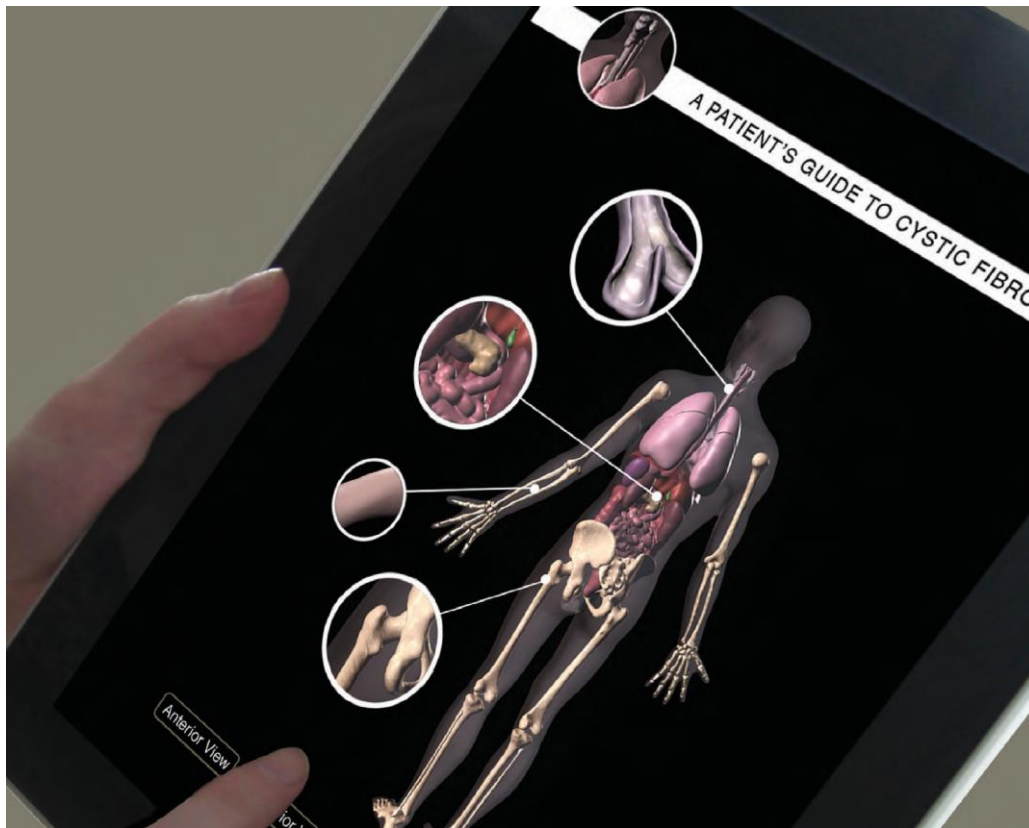designed to support written CF information, and act as a visual navigation interface.

Figure 1: The *'A Patient's Guide to Cystic Fibrosis'* iPad app

For the illustrations, a number of 3D models were created including the human skeleton, skin, lungs and large intestine. A 3D model of the skeleton was produced using publicly accessible, anonymised CT data sets downloaded from the *OsiriX* DICOM Image Library (https://www.osirix-viewer.com/resources/dicom-image-library/). The data sets were volumetrically rendered using *OsiriX DICOM Viewer* software (https://www.osirix-viewer.com/) and the data was tidied using 3D sculpting software *Geomagic Freeform Modelling Plus* v.9.1.2 (https://uk.3dsystems.com/software/geomagic-freeform). A 3D male human skin model was obtained from the *Make Human* project database (http://www.makehumancommunity.org/) and organs were sculpted using virtual 3D clay in *Freeform Modelling Plus*. The models were combined and anatomically

positioned in *Freeform Modelling Plus*, following guidance from anatomists at the

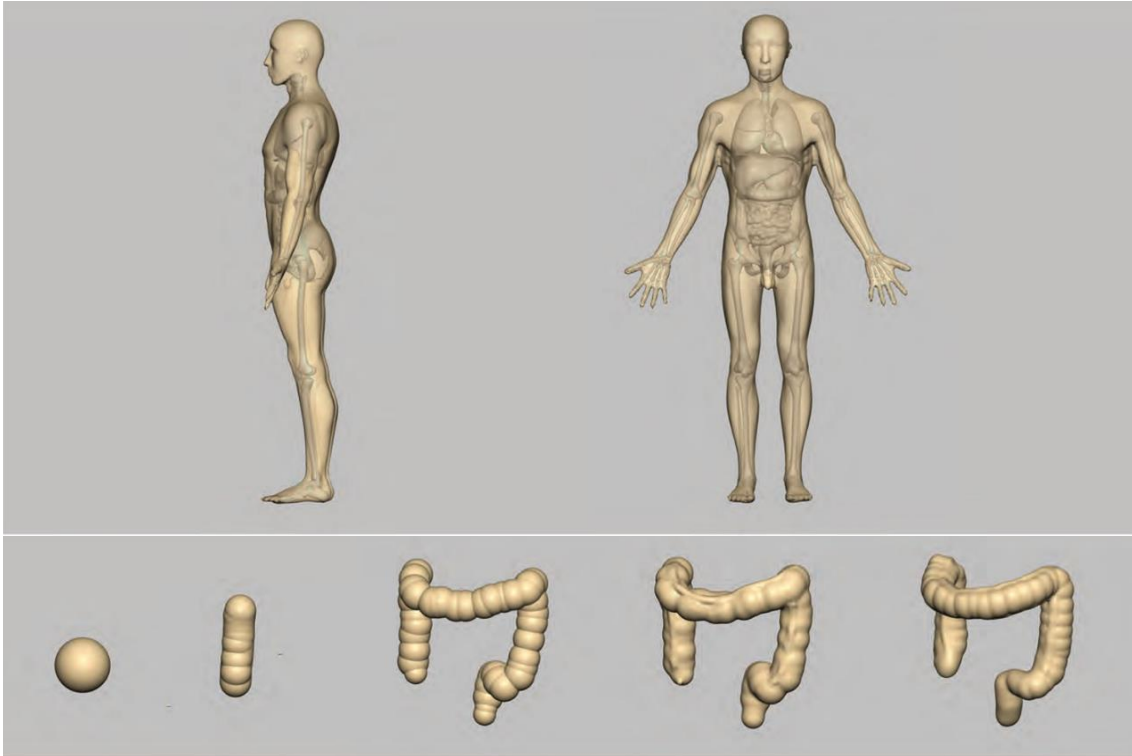Centre for Anatomy and Human Identification (figure 2).



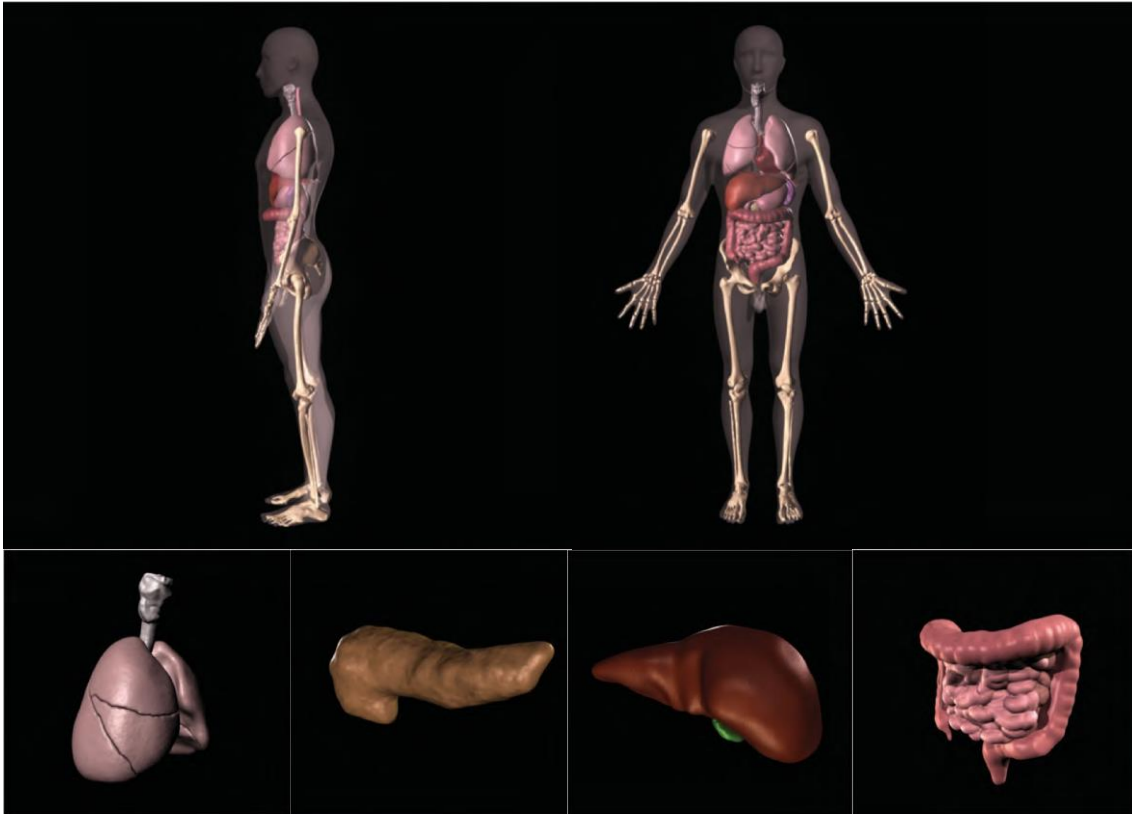Figure 2: Modelling the 3D content in *Geomagic Freeform Modelling Plus* software

Figure 3: Digital texturing and animation of the 3D content in *Autodesk Maya 2010*

The 3D models were exported as .OBJ files to *Autodesk Maya 2010* where they were coloured and rendered as 2D still images (figure 3). 3D models of the lungs, pancreas, intestines and liver, were animated using a 360 degree camera rotation and exported as .AVI movie sequences. Animations of cross-sections of the airways and small intestines showing mucus build-up to compare normal and abnormal physiology were also produced (figures 4 and 5). The 2D rendered 3D illustrations were combined as full-page illustrations using in *Adobe Photoshop CS4* before uploading to the Apple app developer software. Here, interactive navigation features were added.
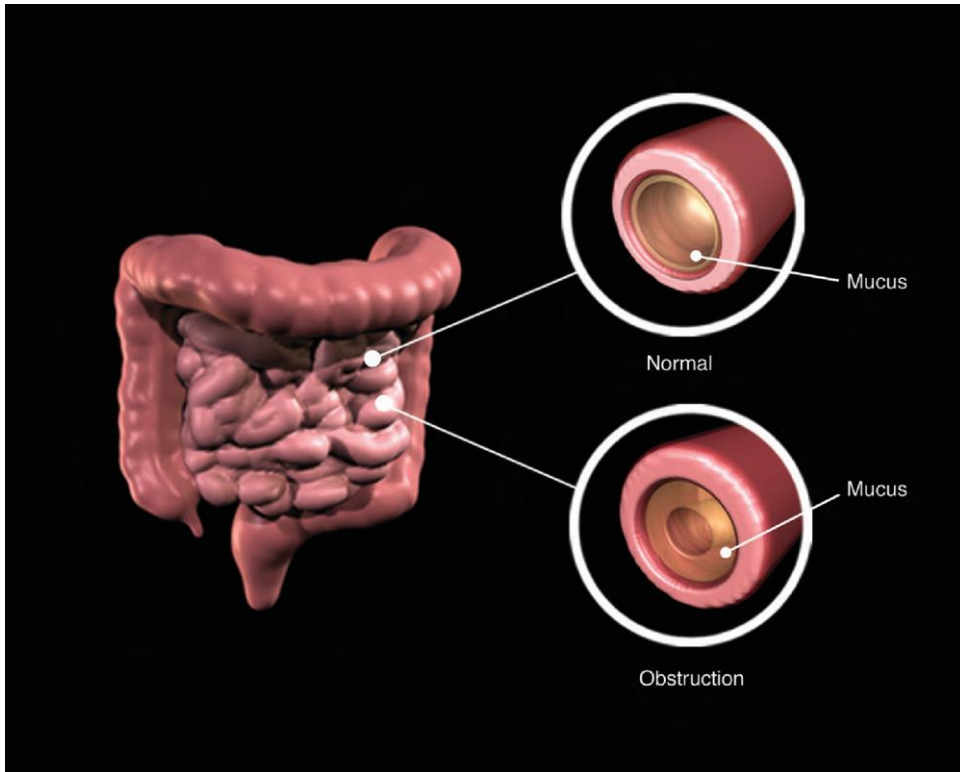
Figure 4: Illustration of Distal Intestinal Instruction composited in *Adobe Photoshop CS4*
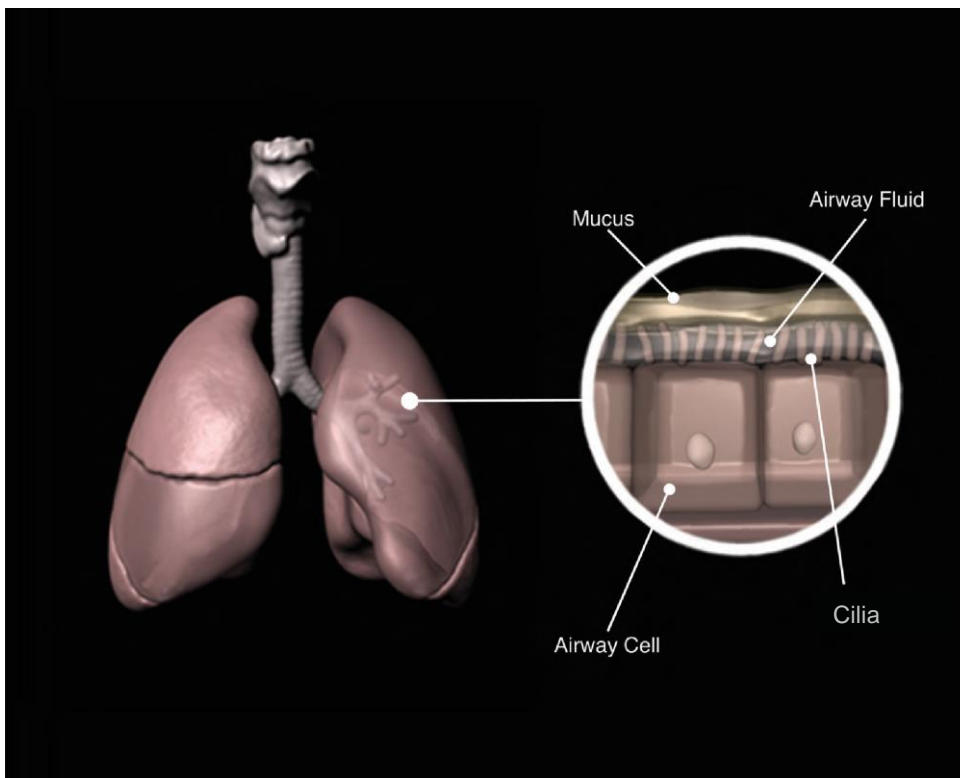
Figure 5: Illustration accompanying descriptions of mucus build-up in the
airways, composited in *Adobe Photoshop CS4*


From the main 'home' screen of the iPad app (figure 6), users were able to
navigate to pages describing CF and its features (with text and further images), and a
step-by-step description of the annual CF review by touching the associated 'buttons' at
the bottom of the screen. Users could also navigate to more in-depth information about
how CF affects the organs and body systems highlighted in the main diagram on the
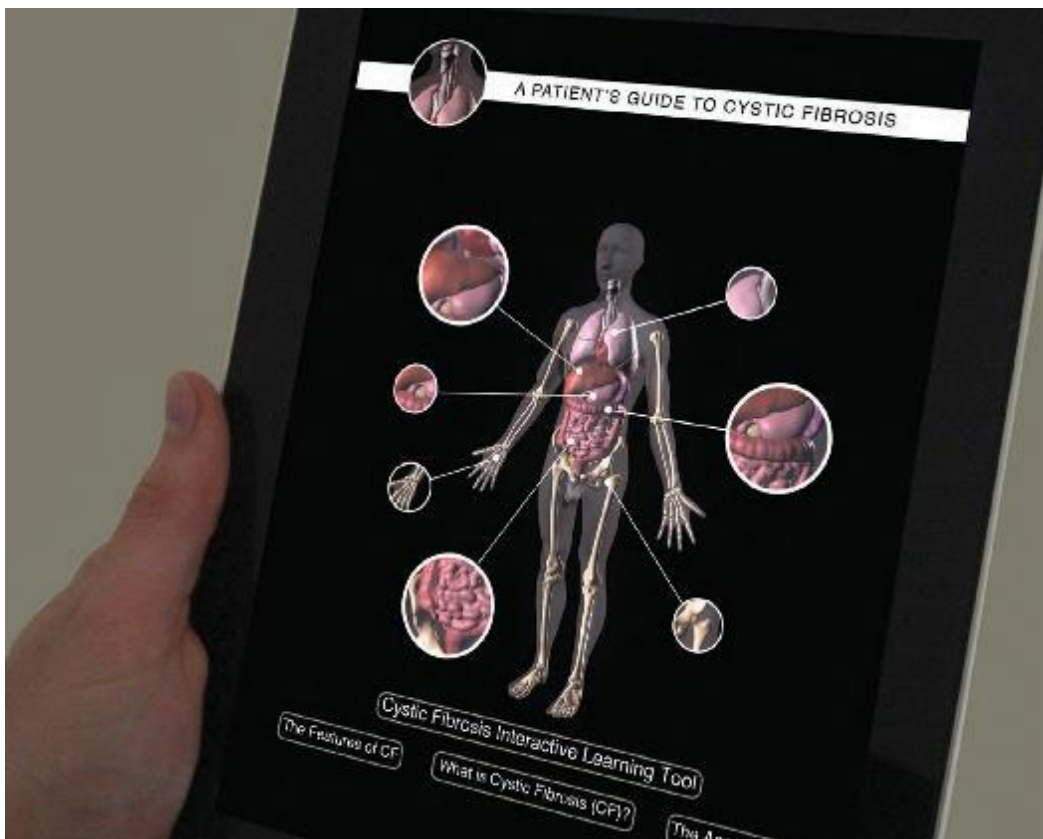home page by touching the circular 'pop-outs'.



Figure 6: Navigational interface of *'A Patient's Guide to Cystic Fibrosis'* iPad
app

Over a five day period in July 2010, sixteen pseudo-patients from the Centre for Anatomy and Human Identification, aged between 19 and 52, user-tested the app with the premise that they had newly been diagnosed with Cystic Fibrosis. Ten NHS staff including CF clinical nurse specialists, respiratory consultants, dieticians and other specialists also tested the app at Ninewells hospital and gave their feedback. It was not possible to gain ethical approval to test the iPad app with NHS patients at Ninewells hospital in the three month period allowed for the completion of the taught-postgraduate research study.

The participants were asked to use the iPad app with verbal instruction on how to use both the iPad and the app by the lead researcher for a total of 15 minutes. Participants then completed a short questionnaire with questions designed to gather feedback on the appearance and content of the application, as well as its usability and the appropriateness for CF patients. The questionnaire comprised of five questions for pseudo-patients and six questions for NHS staff that were answered using a 1-5 Likert evaluation scale; where 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent, and five questions that were answered with a 'Yes,' 'No' or 'Indifferent' response. Participants were also able to leave free-text comments at the end of the questionnaire.

The Cystic Fibrosis iPad app was discontinued in 2014 due to the widening cost and increased skills required to maintain and update the content. Evaluating the content against the findings of Payne, *et al.* (2012) and Briggs, *et al.* (2014), which state the advantages of Apple iBooks as patient information tools, the iPad app was re-developed as an iBook titled '*Cystic Fibrosis: A Pocket Guide'* (figures 7 -10). The iBook can easily be updated by the nurses using Apple's free *iBooks Author* programme, without the need for complex programming skills (Briggs, *et al.* 2014). An Android app version

was also produced with support from developers Nuifish Ltd, to increase access for

those who do not own an Apple device. The iBook version can be downloaded here

https://books.apple.com/gb/book/cystic-fibrosis/id1361573463; and Android version

here

https://play.google.com/store/apps/details?id=com.nuifish.cysticfibrosis&hl=en_GB.



Figure 7: An introductory page from the *'Cystic Fibrosis: A Pocket Guide'* iBook
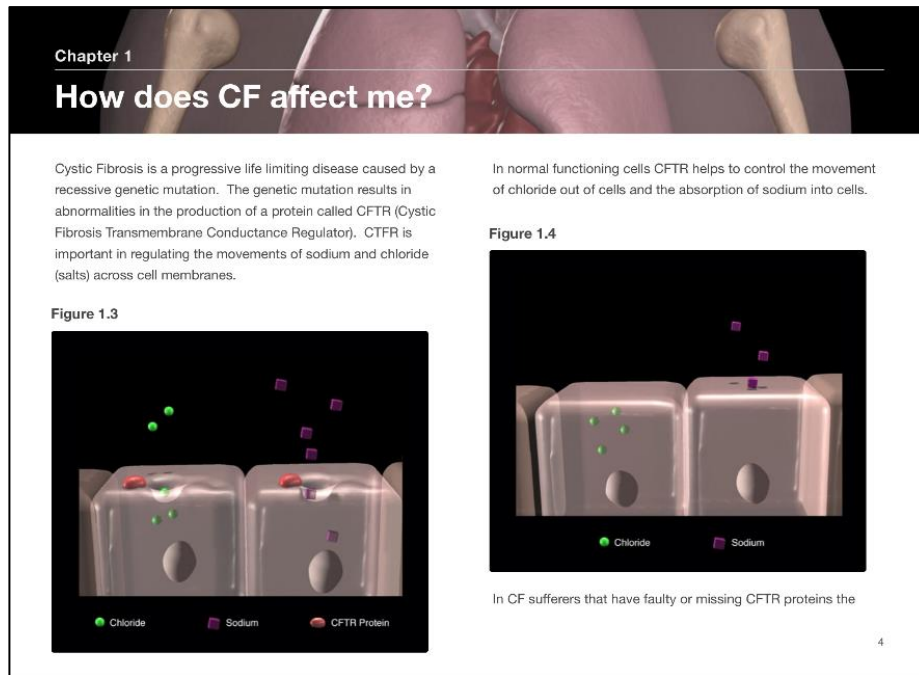
Figure 8: An introductory page from the *'Cystic Fibrosis: A Pocket Guide'*

iBook explaining Cystic Fibrosis Transmembrane Conductance Regulation (CTFR)
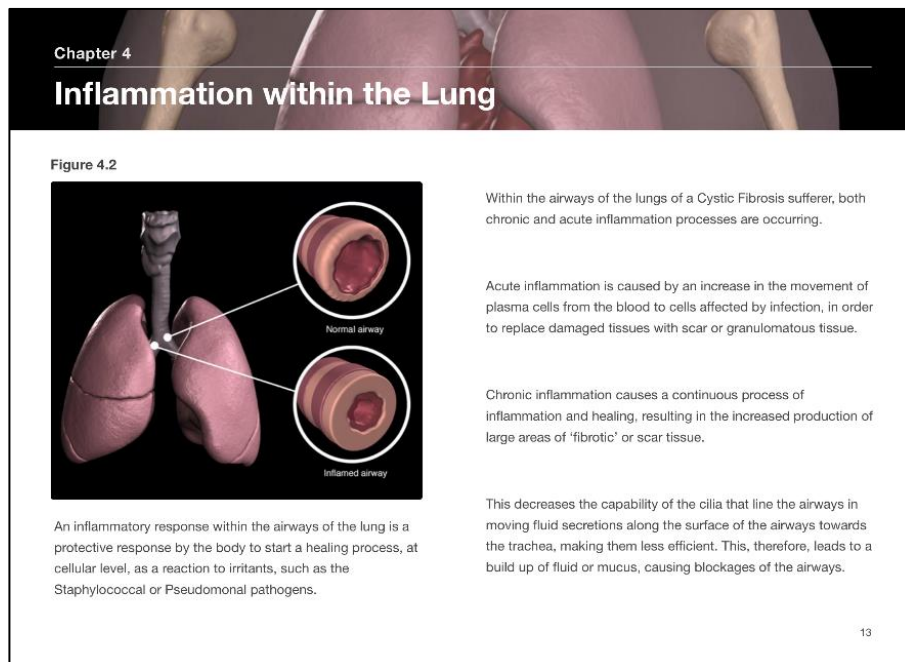


Figure 9: A page from the *'Cystic Fibrosis: A Pocket Guide'* iBook explaining

inflammation within the lung

Figure 10: A page from the *'Cystic Fibrosis: A Pocket Guide'* iBook explaining mucus

build-up within the lung

**Results:**
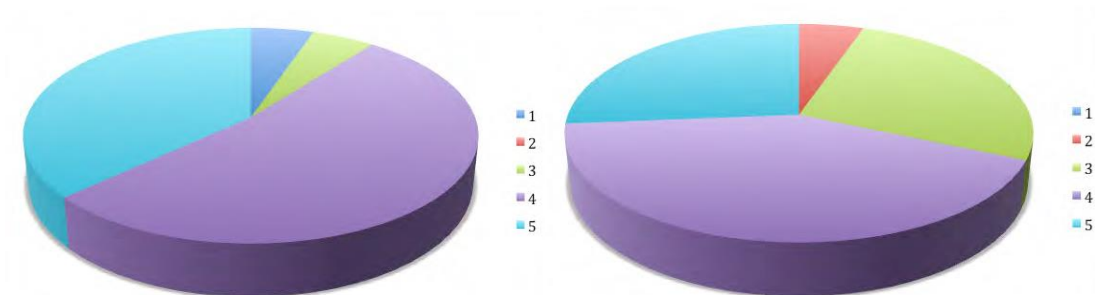


**Question 1:** *How would you rate your experience interacting with the CF patient*

*information app? (Left) pseudo-CF patients, (Right) NHS staff.* 1 = Very poor, 2 = Poor,

3 = Good, 4 = Very good, and 5 = Excellent
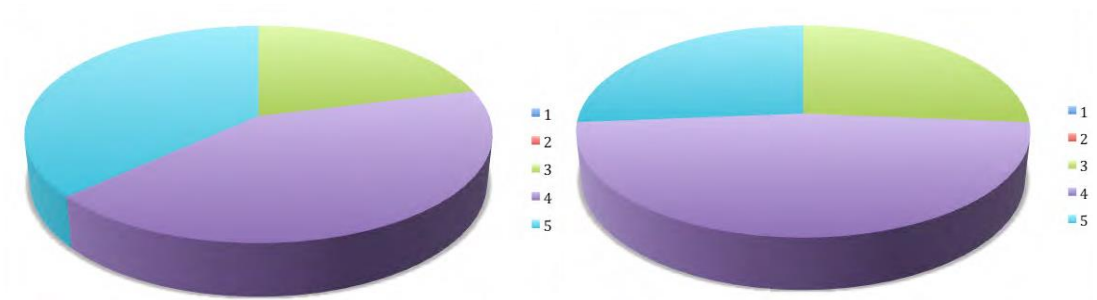
**Question 2:** *How would you rate the usability of the interactive CF patient information app? (Left) pseudo-CF patients, (Right) NHS staff.* 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent
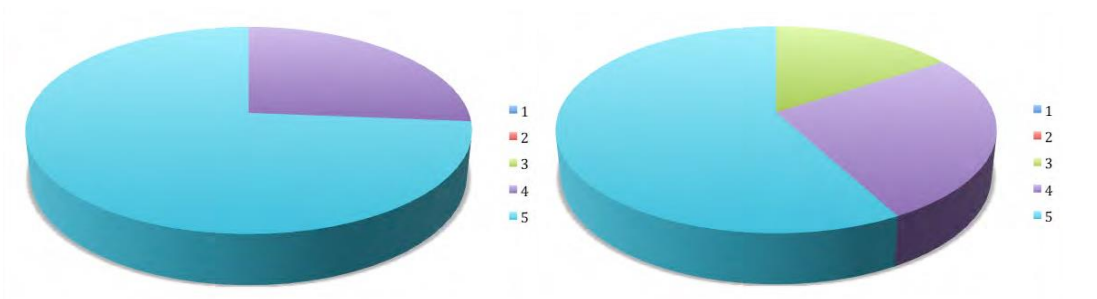


**Question 3:** *How would you rate the appearance of the interactive CF patient information app? (Left) pseudo-CF patients, (Right) NHS staff.* 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent
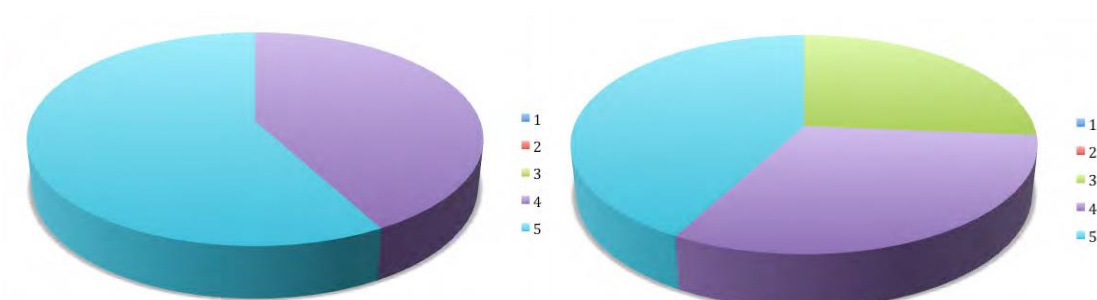


**Question 4:** *How would you rate the level of visual detail in the interactive CF patient information app? (Left) pseudo-CF patients, (Right) NHS staff.* 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent

**Question 5:** *How would you rate the written content of the interactive CF patient information app? (Left) pseudo-CF patients, (Right) NHS staff.* 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent

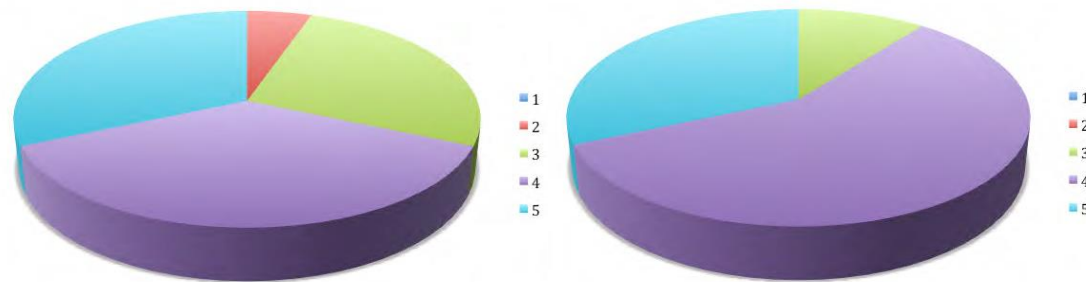Answers to the final five questions showed that 100% of the pseudo-CF patients agreed that the iPad app improved their knowledge of CF and why certain medical tests are required. 95% answered that they would use the app again, however, 79% stated that they would have found it helpful to have a specialist nurse present to answer any questions as they used the app. Overall 95% of the pseudo-CF patients agreed that the content of the app would be appropriate for newly diagnosed Cystic Fibrosis patients.

100% of the NHS staff that completed the questionnaires agreed that the they believe that the iPad app would help to improve a patients understanding of Cystic Fibrosis and why certain medical tests are needed. 84% agreed that the content of the would be appropriate for CF patients, with 95% stating that they would recommend the tool to patients. For the additional question to be answered by NHS staff only, the app was rated highly compared to existing CF patient information tools.
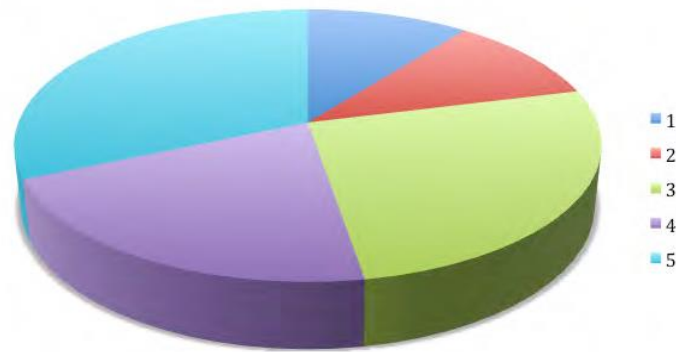
**Question 11:** *How does the interactive CF patient information app rate against existing CF patient information tools? (NHS Staff only).* 1 = Very poor, 2 = Poor, 3 = Good, 4 = Very good, and 5 = Excellent

Feedback provided by the pseudo-CF patients and NHS staff in 2010, agreed that the iPad app was easy to use, was visually appealing, informative and *"possibly more reliable than other information sources e.g. Google, which patients might otherwise use"*. It was possible to conclude that the app would work well as a standalone source of Cystic Fibrosis information for patients at home and to support the annual review process. However, the interactive elements were highlighted as lacking in 'true' interactivity. For example, the movies of the 3D organ models, which were rotating on one axis, could have been more interactive if the user could use their finger to rotate the 3D model in any direction themselves rather than playing and stopping a linear video. It was also noted that the written language appeared too complex in places where the user had no prior knowledge of CF, and that there was a lack of physiotherapy treatment and dietary information.

Between October 2013 and June 2020, the Android app available in the Google Play store had 335 downloads, and received fifteen written reviews and thirty-three star ratings with an overall satisfaction score of 4.5 out of 5 stars. From the fifteen written

reviews, twelve reviewers gave the app 5 stars, and two reviewers gave the app 2 stars. Additionally, one reviewer gave the app 1 star, however, the associated written comments do not relate to the app or its content but to a dislike of the NHS. Written feedback left by reviewers who gave the app 5 stars indicate that the Android app version is informative and user friendly for individuals with CF and their family members, and for those who simply wanted to find out more about CF. One reviewer specifically indicated that the app was helpful for the completion of their university assignments. A reviewer who gave the app 2 stars in 2016 wrote that there is "*not enough information and [it is] not interactive, [and it] doesn't engage the user at all*." Another reviewer notes that the font used in the app might be difficult to read by the visually impaired, and that the font is too small on some pages unless viewed at a larger magnification. This could mean that the text might not meet the DCB1605 Accessible Information Standard (2017).

This feedback is similar to the feedback obtained from users of the original iPad app in 2010 and further highlights the need to update the interactive elements of the guide. The iBook has had a total of 162 downloads from the Apple Books store but no written reviews have been provided. The iBook has a similar satisfaction rating of 4.0 stars, however, this is based on one rating.

The CF clinical nurse specialists and respiratory consultants at Ninewells hospital have continued to use '*Cystic Fibrosis: A Pocket Guide*' in the 10 years since '*A Patient's Guide to Cystic Fibrosis*' was first developed. They report that the pocket guide is a useful adjunct, which supports the continued education and empowerment of those wishing to increase their understanding and knowledge about Cystic Fibrosis. The images are reported to be engaging and users are able to navigate through the content with ease.

**Discussion:**

The aim of this study was to design and create an interactive Cystic Fibrosis (CF) patient information iPad application to aid in the ongoing education and management of Cystic Fibrosis patients. It was the intention that both CF patients and specialist nurses at the Respiratory Unit at Ninewells Hospital, Dundee would use this tool as a visual guide during the annual review process. The re-development on the app as an iBook and Android app was to facilitate learning outside of clinical settings at home and increase access to the resource.

In the 10 years since the '*A Patient's Guide to Cystic Fibrosis'* was created there has been a surge in the number of health apps and multimedia resources available for the public generally, and for CF patients specifically. More than 10 CF iBooks and 25+ Apple and Android apps are available for download. Each version varies widely in relation to the volume of content, balance between images and text, ability to integrate health records or to input own data, and the embedding of videos and diagrams. However, none of the available apps adopt a visual navigation interface similar to '*Cystic Fibrosis: A Pocket Guide'* or include 3D models.

The clinical information in the pocket guide is updated annually, and the content has recently been added to a Scotland-wide 'Learn Pro' module developed by the Scottish CF Nurse Group, which is also accessible through the Tayside Cystic Fibrosis website and University of Dundee University Medical School website. In response to feedback provided by users of the original iPad app and more recent Android app, additional physiotherapy and dietary information was added to the guide, however, the 3D models have remained as movies due to a lack of expertise that is required to make the models interactive. This remains an area of development for the guide, whereby the existing 3D models could be used in more interactive touch-based experiences. Research shows that 3D interactive models enhance learning for novice learners and are

capable of motivating and aiding in memory recall and visualisation for experienced learners (Pacheco, *et al.* 2017).

A simple solution would be to save the existing 3D models as .dae file types and embed them into the iBook version using the '3D widget' tool in *iBooks Author*. The models can then be rotated or zoomed into through touch-based gestures. However, the inclusion of multiple 3D files in one iBook via this method means that the 3D models are stored locally, making the iBook file size very large and this can take up a lot of space on the user's device (Erolin, 2019). Alternatively, 3D models created in *KeyShotXR* (https://www.keyshot.com/web/) can be exported using the 'Create iBooks Widget' from the 'Render Ouput' window. This creates a HTML5 .wdgt file, which is a zipped file format and compresses the size of the models. The .wgt can be embedded into an iBook using *iBooks Author* by choosing *Insert > Widget > HTML* in the *iBooks Author* menu and then selecting the required .wgt file (Wallaert, 2019).

It is notable that apps available in the Apple and Google Play stores are often unregulated. Similar issues in relation to the reliability of health information presented on the Internet, also apply to information contained in health apps (Moodley, *et al.* 2013). Especially where users approach learning from a singular source. It is hoped that by using the current versions of the UK Cystic Fibrosis Trust 'Standards of Care' documents as a basis for the information presented in '*Cystic Fibrosis: A Pocket Guide'*, with additional commentary based on the specialist CF nurses years of experience, that the resource is deemed as reliable and trustworthy source of information.

Patient families and their wider social groups are active users of the guide at various junctions through their CF journey. The CF clinical nurse specialists also use the guide as a teaching aid for the many learners who work with the nurses as part of

their higher education programmes. This includes physiotherapists, nursing and medical students, as well as visiting international doctors who visit the Respiratory Unit via research programmes.

**Conclusions**

'*Cystic Fibrosis: A Pocket Guide*' continues to be an integral educational tool and has been used regularly since '*A Patient's Guide to Cystic Fibrosis*' was first developed. Recent iterations of the guide continue to utilise impactful visual interfaces, supported by bold and colourful images that are popular with users of the guide. The written clinical information is updated regularly, and plans are in place to embed touch-based, interactions with the 3D models in future versions.

In July 2020, Apple announced that the standalone *iBooks Author* app will no longer be supported. While users who previously downloaded the app can continue to use it on macOS 10.15 and earlier, iBook creation has moved to the Apple *Pages* app (https://support.apple.com/en-us/HT211136). Currently, *Pages* is able to import existing iBooks and allows the user to edit some content, however, if an iBook is imported that contains 3D models, the app creates a folder for all 3D models used in the iBook on the computer's local disk. These 3D models can opened in *Preview* and saved as a movie using *QuickTime* but cannot be viewed within *Pages* or the iBook itself. There is no provision that allows new 3D models to be embedded into a new or existing iBook. (https://support.apple.com/en-us/HT211135). This will create additional challenges and maintenance issues for the CF nurses. It is possible that future versions of '*Cystic Fibrosis: A Pocket Guide*' will not be available in iBook format but instead as identical Apple and Android apps.

At the time of writing, the CF clinical nurses are in consultation with app developers to develop an updated version of the guide that will closely monitor

adherence to the DCB1605 Accessible Information Standard (2017), and also incorporate a secure area where patient specific information can be uploaded, meaning patients will have instant and mobile access to personal locked information such as genotype, bacterial colonisation and medication lists.

Medical teams caring for those with other illness groups have been keen to adopt and modify the pocket guide framework to their own specifications, and the CF clinical nurse specialists are currently investigating ways to accommodate this for the wider benefit of patient communities.

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